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Genetics and Justice: must one theory fit all contexts?

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Abstract

Appeals to social justice that argue medicine and health care should have certain priorities and not others are common. It is an obvious question to ask what social justice demands of the new genetic technologies. However, it is important to note that there are many theories of justice and sub-theories. There are utilitarian theories, libertarian theories, and egalitarian theories. There are so-called luck egalitarians, equality-a-fairness thinkers, and capability theorists, with each having its own distinctive approach to the distribution of medical goods and technologies and health care priorities. This paper argues that the discussion surrounding this question is potentially hampered by an implicit assumption: that if one theory of justice is applicable in one context, then it must also be applicable in others. Instead, it is proposed that we adopt the stance, influenced by Michael Waltzer, that different theories with their opposing principles may be applicable to different questions regarding justice and genetics. The specific view advanced is that in order to answer questions regarding what justice requires regarding the therapeutic and enhancement use of genetic techniques, a method of reflective equilibrium can show us how our intuitions, in context, may support different theories of justice. When our particular pre-theoretic ethical judgments are balanced against the theories that might explain or justify them, and are in accord with what seems emotionally acceptable, then we can see how different general theories may be applicable in the different contexts in which questions of justice and genetics arise.

Key words: theories of justice; bioethics; genetics; context

Genetics and Justice: must one theory fit all contexts?

1. Introduction

Discussions of social justice arguing that medicine and health care should have certain priorities and not others are commonplace in the bioethical literature.¹ Indeed, this is no surprise given that social justice appears as one of the key tenets of the dominant principlist approach.² Genomic research, genetic therapies, and possibly enhancements, have long been discussed by bioethicists, with the intensity of the discussion tending to ebb and flow according to the state of the research and technology at the time. Very recently, with the development of the CRISPR³ technique for editing DNA, ethical discussions about the potential uses of genetic technologies have been given a new urgency. It is, therefore, an obvious question to ask, again, what social justice demands of the new genetic technologies.

Theories of distributive justice concern the distribution of goods within society. They predominantly concern the role of the State and what its obligations are with respect to the distribution of these goods. Usually, it is basic or so-called ‘Primary’ goods that are discussed. These are the sort of thing that everyone might want or need in order to lead a good and fulfilling life. It is also common in the literature to distinguish between so-called ‘Social Primary Goods’⁴ which may include economic resources, healthcare and education. They are goods whose distribution societies can affect. On the other hand, there are ‘Natural Primary Goods’.⁵ Some people are naturally smart, some live longer, some have greater imagination and vitality, some are considered handsome etc. Just exactly what should be on either list is debateable, but whatever the details, they could be very general goods that everyone could be expected to want or need to pursue their life plans. Up until fairly recently the ‘Natural Primary Goods’ – intelligence, physical potential etc. – were not thought to trigger distributive justice concerns because it was thought that we could do very little, directly, about them. Perhaps in some cases there were ‘social determinants’ that could be addressed, such as special education for those with such needs, but the physical basis for a lot of these things was not addressed as a matter of justice, falling under other concepts such as luck or misfortune.

Even if one holds the view that some these natural inequalities should trigger distributive justice concerns, the practical possibilities for addressing them have been limited to the redistribution of social goods as a form of compensation. One might see progressive taxation as one such means. However, as scientists and bioethicists are starting to realise, the advances in genetic technology promise that more and more of these differences, insofar as they have a genetic basis, could be eradicated directly. So, for example, if we think that justice requires that we ‘level the playing field’ in the ‘game of life’ then justice might require policies regarding access to genetic technologies.

¹ For example, Farrelly thinks that we should all be ‘prioritarians’. Farrelly, C. (2005) Justice in the Genetically Transformed Society *Kennedy Institute of Ethics Journal* vol15, No.1 91-99.

² Beauchamp, T. L. and J. F. Childress (1979). *Principles of biomedical ethics*. New York, Oxford University Press.

³ Jinek, M., Chylinski, K., Fonfara, I., Hauer, M., Doudna, J.A. and Charpentier, E., (2012). A programmable dual-RNA-guided DNA endonuclease in adaptive bacterial immunity. *Science*, Vol.337(6096), pp.816-821.

⁴ Rawls, J. 1999. *A Theory of Justice*. 2^o ed. Cambridge, MA: Harvard University Press.p, 79.

⁵ Rawls 1999, p, 54

Assuming that many of the promises for genetic technology such as curing disease (e.g. Muscular Dystrophy, Cystic Fibrosis); improving or enhancing traits such as intelligence, strength, and longevity, by replacing or modifying genes or through genetic pharmacology, are realised, a cluster of questions suggest themselves. What should justice require of us (or the State) regarding genes and genetic technology? Should it do nothing, or should the State be required to intervene at the genetic level, to modify people who are 'disadvantaged' by their genetic endowment?

2. Two kinds of question

In contemplating such a question we are immediately confronted by two other kinds of question. The first question we need answering is which theory of social justice are we talking about? Which raises an important subsidiary question: how could we decide which theory we are to invoke when answering the main question?

If there was a consensus over which theory to invoke, then there would be only the, admittedly formidable task, of working through the technicalities of its applications. Unfortunately, there is no such consensus. There are utilitarian theories,⁶ libertarian theories,⁷ and justice-as-fairness thinkers.⁸ There are egalitarian theories with their sub-theories such as the so-called luck egalitarians, as well as capability theorists. Of course, some of these will overlap with each other, sharing premises or conceptual ideas. Despite some overlap, each of the main theories represents a distinctive approach to the general distribution of goods, and to medical goods and access to technologies and health care in particular, which arguably includes the new genetic technologies.

One reason for this lack of consensus is that each of the main theories of justice can be defended against its rivals because they each give expression to powerful and deeply felt intuitions about justice matters that are to be found in our societies. For example, many people feel that all or most of the following moral principles are important:

1. It is important that the distribution of goods is fair.
2. It is important to help as many people as we can.
3. People should take responsibility for their actions.
4. The distribution of goods should reflect what people deserve.
5. People should be free to chart their own course in life with minimal state interference.

⁶ Utilitarianism has undergone many refinements since the early statements of the doctrine from J.S. Mill, Bentham and Sidgwick. What remains is the basic idea that we should do that which maximises utility for as many as possible.

⁷ The classic statement of libertarian justice is to be found in: Nozick, Robert, 1974, *Anarchy, State and Utopia* New York: Basic.

⁸ Rawls' 1999, *A Theory of Justice*. is considered to be the modern initiator of discussions of justice-as-fairness, as well as offering a refinements to the role of equality in the theory of justice. Other statemts of his views can be found in Rawls, John 1993. *Political Liberalism*, New York, Columbia University Press, and in Rawls, J. 2001. *Justice as Fairness: A Restatement.*, Cambridge, Harvard University Press.

No doubt there are others too. Each of these is connected conceptually with different theories of justice. 1 can be identified with the Rawlsian approaches to justice, whereas 2 seems more utilitarian. One might think that 3, 4 and 5 are more in line with a libertarian approach. Perhaps, suitably interpreted, they may be accommodated by the other theories as well.

The question of justice and genetics is complicated because of the existence of different theories of justice, some of which will give conflicting answers to the question of what the State should do. Here I do not propose to try and ‘prove’ that one theory is the correct one. Instead, for present purposes it is assumed, without argument, that there is reasonable support for approaches to justice that are broadly Utilitarian, Libertarian and those that emphasise Fairness, in the tradition started by Rawls.

As we know, there is extensive literature on all these and I don’t intend to do much more than offer the most basic sketch. Simplifying, we can say that Utilitarianism requires that the State aim to maximise the total utility in society. What counts as utility may differ depending on the theorist preferred, with the usual candidates being pleasure, happiness, or, more recently, the satisfaction of preferences. Assuming the latter, the State has a duty to ensure that as many people as possible have the means and conditions to achieving their chosen conception of a good life.

One of the numerous problems associated with this approach is the way in which the focus on the aggregate of social utility, as a measure of just outcomes, conflicts with other intuitions people may have about justice. As Rawls once observed, Utilitarianism does not recognise the “...the separateness of persons...” This captures a strong intuition about justice such that if individuals make sacrifices, then they ought to reap whatever benefits those sacrifices yield. Therefore it would be morally objectionable to make some people suffer in order that others may be better off. Utilitarianism, it might be contended, merely focuses on aggregate social utility and therefore it is blind to this idea of justice being constrained by what people deserve. With policies fashioned under the influence of Utilitarian philosophy, it may not be the same people who experience the losses and gains. For example, this could happen by diverting the money to pay for access to genetic therapies or enhancements at the expense of budget cuts elsewhere, or vice versa. So, averaging utility may lead to (intuitively) unjust arrangements. And, more generally, efficiency regarding maximising utility isn’t the only consideration regarding justice.

Libertarianism as a theory of justice requires that everyone be free to pursue their conception of the good life, as long as doing so does not interfere with that right for others. The State should therefore have minimal involvement in the lives of its citizens, notwithstanding that the State’s resources will be involved in upholding rights to pursue individual goods and the good life. The main problems with such a conception of libertarianism concern what some regard as a general failure to recognise the extent to which people within societies are interconnected. Recognising this puts greater restrictions on individual freedom and more legal and regulatory duties on the State; we cannot do anything we like, or with our property, because our actions can seriously affect others and the societies in which we live.

Justice-as-Fairness requires equal liberty and opportunity for all, with the proviso that if there are to be inequalities, the State should prioritise some before others. The least well-off should benefit the most: the sick should come before the healthy. In this sense we might use the label 'prioritarian' to distinguish the approach from egalitarian views that make no such caveat.⁹

Problems with this approach might include the prominence given to intuitions about justice. Intuitions can be flawed. Rawls relies, to a certain extent, on his readers' intuitions about 'what is fair' as being the same as his. As noted already, there are other possibilities which may seem attractive.

Without rehearsing in detail the well-known argumentative devices invoked by Rawls to address this, we should note that the most striking argument invokes the idea of an 'Original Position' where principles of justice are decided on the basis of not knowing which social group one might be in. The thought here is that this would yield the broadly egalitarian principles that Rawls' theory is built on. However, the justificatory force of the Original Position has been questioned because the contract is 'rigged' to yield principles that are in line with our intuitions.¹⁰

Clearly a lot more could be said here both in terms of the detail of the theories, and an elaboration of the objections to them. For present purposes this is not necessary. All that it is necessary to have established is that there are different theories of justice – not exhaustively captured by the three discussed here – that they all have problems, and that each reflects some plausible intuition that relates to justice matters.

One way of addressing the question 'which theory of justice' would be by demonstrating that there is only one valid or reasonable candidate, and then applying it to all cases to see what just outcomes might be. However, 'foundationalist' approaches, where one theory is proved to be 'the one', are now regarded with suspicion. This has led to the rise of so-called 'coherentist' methodologies such as 'reflective equilibrium' invoked by Rawls and others. My own approach is to adopt a very simple 'reflective equilibrium' approach. The method of reflective equilibrium involves moving between our judgments, or intuitions, about particular cases and the principles and theories thought to be relevant in order to achieve an acceptable coherence – a reflective equilibrium – among them. This will involve me sketching what I take the different theories to be committed to regarding genes and their distribution as goods. But it also means taking into account intuitions regarding justice in the different contexts, as well as the implications for action drawn from theory.

When it comes to genes, it is my contention that the combination of initial judgements, or intuitions, with justice theory, and wider morally relevant beliefs, supports the conclusion that the 'correctness' of a theory of justice will depend on the context in which the question arises.¹¹

⁹ Colin Farrelly's *Genetic Difference Principle*, as a modification of Rawls' framework, develops this idea. See Farrelly, C. (2004). The Genetic Difference Principle. *American Journal of Bioethics* 4: 21-28.

¹⁰ For example see Hare, R.M. (1973) 'Rawls' Theory of Justice', *Philosophical Quarterly*, 23:144-55; 241-5.

¹¹ The idea of different principles of justice being applicable in different contexts, without contradiction, can be found in Michael Waltzer's book: Waltzer, M (1983) *Spheres of Justice: A defence of Pluralism and Equality* Oxford; Robertson..

What I want to suggest is that rather than one having to be a Utilitarian or a Prioritarian or a Libertarian on the questions of justice and genetics, one may well be all of them (or some mixture) depending on the particular context in which the question of justice arises. Our intuitions regarding the different contexts may be in 'reflective equilibrium' with different theories. This does not, however, answer the question which theory in the particular context should be invoked, simply because my intuitions might be different from yours. Still, here I sketch three slightly different contexts in which the question of justice and genes might arise.

3. Scenario 1.

Let us imagine that in the not-too-distant future genetics offers several possibilities for prospective parents who fear their off-spring might be affected by Cystic Fibrosis. CF is a monogenetic disease caused by a mutation of the CFTR gene that affects the lungs of sufferers. In this imagined scenario there are at least two possibilities for parents. The first is to screen embryos via PGD to make sure the defective gene is not passed on. The second imagined possibility is gene therapy after the child is born and diagnosed. Let us further assume the second option is the most popular. So, the question here is what should the State do, what are its obligations with respect to the parents and child in this case? Assuming, plausibly, that the State has finite resources at its disposal, what would the theories say?

Utilitarian: The State should maximise utility by making as many as possible happy. However, if the cost of gene therapy is high (as it may well be), then we might not be able to afford it. Treating one person might be at the expense of, say, 50 new hips or some other use for the money that yields even more utility. So, expensive therapy may not maximise utility, and therefore might not be prioritised.

Libertarian: It is the responsibility of the parents to seek medical help, and pay for it. Perhaps, it is their responsibility not to have kids if they know they are carriers. Or, if they do, they should pay for screening and PGD or gene therapy, and only have healthy kids, unless they are willing to pay for the kids' healthcare.

On the other hand, they might insist that one of the State's (few) obligations is to uphold the basic freedoms of citizens. If one of these is the right to have children, it might be contended that the State has a duty to help people achieve this, which may include ensuring the children are healthy.

Fairness: A loosely Rawlsian-type theory, based on his difference principle, may say that if there are to be inequalities, then the State should ensure the arrangements favour the worst off. So, the State should target the sick first, and the sickest should be right at the front of the queue. This would seem on the face of it to imply that children with severe illness should get priority treatment.

Some intuitions

On reflection I conclude that mine are prioritarian. On further reflection, my intuitions about this scenario seem to include, amongst other things:

1. Those who are sick through no fault of their own deserve help.
2. Individuals' freedom should be protected; this may include rights to health.
3. Maximising utility is not always the right thing to do.
4. It may sometimes be unjust for the State to pay for expensive treatments for a few.

Reflective equilibrium as a method of settling on a theory, as noted above, has it that we should see which principles result from our intuitions, and then which theories are most compatible. We might also seek to widen the equilibrium by subjecting the theories and judgements to criticism from other perspectives. Of course, if we have different intuitions, then we might be committed to different theories of justice.

Such a process would be time consuming, but it suggests that when it comes to sick people *my* intuitions are more in line with **justice as fairness**. Indeed, Rawls himself also thought that justice as fairness was what emerged from the process of reflective equilibrium, although he conceived of it as the general framework rather than just contextually applicable. That is, the Rawlsian approach is thought to apply to all contexts. The problem for such an approach seeking to identify 'the one' true theory, or the one theory that best coheres with all our other beliefs, is that in other contexts our intuitions might be different. That is, when the circumstances of application are different, other theories may start to seem more attractive. This is, of course, only a problem if one thinks that only one theory should be applicable across all contexts. Given that intuitions, or considered judgements, are always about specific contexts, and given that the rules and theories they support may change with changes in judgement and context, it seems to follow that there can be multiple theories of justice some of which will be applicable in some contexts and others when the context or circumstances change.

4. Scenario 2

Imagine that the planet's atmosphere deteriorates to such an extent that humans start to develop skin cancer at alarming rates. There are some who are immune, but the vast majority of people are not. Suppose further that it is discovered that there is a pigment in the skin that protects against the cancer, which worked effectively (in most people and still does in a few) until the atmosphere degenerated. There is a therapy (or enhancement if you will), that can increase the level of cancer-protecting skin pigment so that all could potentially be made resistant to the cancer. The therapy in question involves gene modification. In terms of the theories we have been considering:

Utilitarian: The State should treat as many as possible; a maximising strategy to get as many over the threshold is required.

Libertarian: People should weigh up their options and if they wish to have the therapy, pay for it. If they cannot pay, then presumably they need to stay in doors. But, of course, then people are not free to do what they want. So, even the libertarian might have to seek some State involvement.

Fairness: There is no question of someone being worst off genetically here. You either reach the threshold or you do not. It is all or nothing. One might argue that the majority are the worst off and the few that are immune are the better off, and seek to suggest that a prioritarian theory does fit here. However, in this imagined case, the numbers of immune people are so small that almost all people are in the same situation. So, there is no sense to prioritising treatment on the basis of genomes. If resources are limited, it might make sense to prioritise those who are financially worst off – perhaps means test the treatment – but the aim would still be utilitarian: that is to treat the maximum number of people.¹²

More intuitions

No doubt there are many thoughts, intuitions and ‘considered judgements’ that might be relevant here, but my own intuitions seem to accord with a Utilitarian approach. In particular, the following rules seem to me to apply in this case:

1. The State should help as many as possible.
2. This is a legitimate use of public money.
3. Distribution should be fair, where applicable.

In this case there is a genetic minimum, a threshold. It is discovered that levels of pigmentation over the threshold protect against cancer. In this case, my intuitions are in accord with a utilitarian strategy involving maximising the number treated. In this context, we might see ourselves as utilitarians. No doubt one could work through the detailed implications for rules and principles of adopting this approach in this context, but we can see how a change in context leads to a different conception of justice and what it requires.

5. Scenario 3: The ‘enhancement package’

The third scenario focuses on what may be possible should the promise of the current research be fulfilled. It is certainly conceivable that the kinds of technology developed currently for the treatment of disease – drugs acting on genes, vectors for gene transmission, CRISPR techniques for removing and adding to DNA, and so on – could be also utilised for purposes that are not for the curing of disease, or indeed for things such as imagined in scenario 2, but for non-therapeutic enhancement purposes. To coin a phrase, the new technologies may be utilised to make people ‘better than well’.

Let us suppose that, for those that are able to afford such things, genetic enhancement packages become available on the commercial market. Such packages, rather like cosmetic surgery, are deemed safe, in a narrow physical sense, and there are many traits that can be selected for. This could be for individuals themselves or for their children. Let us suppose further that it is safe for prospective parents to have their own germ cells modified so as to ensure that any subsequent children have the desired characteristics. The parents can opt for a ‘package’ of germ line interventions to enhance their children. The traits affected could include a combination of enhanced height, strength, longevity, resistance to disease, and intelligence.¹³

¹² If the scenario had been different, then intuitions might be different, perhaps activating Prioritarian views.

¹³ I am aware that none of these are actually possible now, and arguably, a general intelligence procedure never will be, but this license with the scientific reality is taken to make the point regarding what the theories should say. See:

What should the different theories of justice say on the matter? Other than ensuring adequate regulation for the safety of the procedures, should the State intervene here as a matter of social justice? Assuming here, as for the other two scenarios, that the State has limited resources, we can sketch the following answers.

Utilitarian: It is hard to say what maximising utility would amount to. If the State has limited resources then it may well decide that those are better spent elsewhere, even though the capacity to live life may be improved. Thus the State has no absolute obligation to provide access to this technology in advance of utility calculations. It might be argued, as we saw in scenario 1, that the money is better spent aiming to give as many people as possible basic healthcare, and possibly curing some genetic diseases, rather than enhancing those that are already well, even though it may increase utility for them.

On the other hand, if we ignore the wider context of State resources and how they could perhaps be deployed in other ways to greater effect, the utilitarian would be committed to enhancing as many people as possible. Maximum utility might be achieved by enhancing a limited number quite significantly, or alternatively, by enhancing a larger number but to a lower level. Given that it is also an egalitarian philosophy perhaps everyone should get the same.

Fairness: If there are to be inequalities, the State should ensure that the arrangements favour the worst off. But, who are the worst off? Assuming that people do fall within the 'normal range', then it is not clear that we can say that people are 'worse off'. Some may be taller, stronger etc, but not to such a degree that we would say that others are disadvantaged. Perhaps we should say they are different.

Libertarian: The State has no obligation to provide access to this technology and certainly has no obligation to fund it. However, people should be free to spend their own money on what they wish, within reason. This certainly includes self-improvement for individuals and their children. According to this view, the State has no business interfering in this. But, neither has it an obligation to enhance other people, especially using tax payers' money. In this respect the theory seems to be in accord with the utilitarian option.

Some further intuitions

1. When we are talking about State resources, it is hard to see how the State could be obligated to enhance people, particularly if we are not talking about curing illness, or if the situation is analogous to scenario 2.
2. On the plausible assumption that enhancement really does mean improvement of lives, and that individuals rather than the state are (usually) best placed to decide what this entails, the State should not restrict people from enhancing themselves and their offspring. In other words, justice here requires the state to facilitate the choices that people may make.
3. This comes with some obvious caveats such as the State should:

- a. Regulate to prevent crazy, misguided, or potentially harmful enhancements, particularly of offspring.
- b. Monitor the uptake of genetic enhancement technologies to make sure that social inequality does not increase to corrosive levels.

What do these intuitions suggest? Certainly utilitarianism would require that the state fund enhancements providing that two necessary conditions are met: the State has unlimited resources; enhancements are genuinely life-improving. The latter is plausible, but unfortunately the former is not the case. Therefore with limited resources at its disposal the State is not obliged to fund enhancement for citizens as it may well be able to do more good for the money available.

With respect to the prioritarian justice-as-fairness approach, my own intuitions seem to imply that the state should be silent on the issue. However, in terms of equality of opportunity to access these technologies, it is possible to see how one might take a more, or less, interventionist position with respect to State obligation. For example, if it is regarded that equality of access to such technologies is met in the same way that the equality requirement is met with respect to other goods, by equal access via the market for those goods, then arguably the state has no duty to discharge. On the other hand, if equality is regarded as restricted by not having the resources to access enhancements, then perhaps the state had an obligation to redress this inequality by funding enhancements for the most financially needy.

On balance, the intuitions sketched above probably support the view that in this context libertarian justice is appropriate, whilst noting that the anti-State thrust of this theory actually requires State involvement in supporting the freedom to enhance. Considered judgements about: the non-enhanced people are not ill; individuals may still want to have these procedures; they may constitute an improvement in their lives support this conclusion.

5. Conclusion

The main burden of this paper has been to persuade that answering the question of what justice requires of States regarding the distribution of 'genetic goods' depends on a number of things. The first thing to note is the plurality of theories of justice. If social justice is to do ethical work in the field of bioethics, then the starting point is to acknowledge that, even though we may have our own favoured theory, there are others. Recognising that there are a number of reasonable yet different theories of justice, and taking this seriously, is necessary for 'justice' to earn its place at the bioethical table. The second thing, which is a corollary of the first, is to acknowledge that the main theories of justice actually reflect some deeply held intuitions that many people have about what is just and what we should do; intuitions about fairness, the general good, non-interference by the state, individual freedom to name a few. This point can be pressed further. Not only is it important to recognise the differences and their rootedness in incompatible intuitions, but also that the intuitions are not obviously wrong. They have reasonable arguments that could be marshalled in support of them. The third point advanced here is that our intuitions about justice, which form part of the process for elaborating and justifying theories, may shift from context to context. If our intuitions are important in grounding a theory of justice, as many commentators following Rawls think, then noting that a change in context can affect which considered judgements about a case we will be inclined to make leads to the conclusion that one theory need

not fit all contexts. Indeed, pushing this a bit further, one might speculate that reason that discussions of justice in bioethics have not progressed very far, beyond working out what the technical application of a theory would involve, is precisely because of the assumption that one theory must fit all cases. Abandoning this assumption may allow ethicists to appreciate that they do not have to wait for the one true theory. All may have something to offer, in certain contexts.